Family Focused Learning: A Model for Learning from Children with Disabilities and Their Families via Technologies for Voice

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Abstract: In this paper, we describe a collaborative multidisciplinary model for faculty and students learning about culture and children with disabilities and their families in Pacific Island contexts. The model, Family Focused Learning, incorporates aspects of case-based and problem-based learning within the context of "consumer" and "professional" partnerships (Ratliffe, Stodden, & Robinson, 2000; Robinson, 1999). Children with disabilities and their families share the daily challenges and successes of their lives with graduate students and faculty at the University of Hawai'i, via *video letters, video mapping, cultural brokering* and *satellite videoconferencing*. To illustrate this process, we present the story of "Tomasi," a child with cerebral palsy in American Samoa, a US territory. Tomasi and his family are "given voice" and act as teachers for an interdisciplinary team of faculty and students from public health, social work, physical therapy, speech pathology, nursing, special education, nutrition, medicine, political science and law.

Key Words: Video Conferencing, family focus, learning communities

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Introduction

The Center on Disability Studies at the University of Hawai'i has a demonstrated commitment to "giving voice" to persons with disabilities and their families. This commitment to self-determination includes technology and media applications that support dialogue, partnerships and synergy among "professionals" and "consumers." This article describes an innovative project entitled "Family Focused Learning" that employed video letters, video mapping, cultural brokering and teleconferencing to promote cross-cultural communication and consumer empowerment between UH faculty and students, and an economically disadvantaged family in American Samoa who have a child with severe cerebral palsy.

In this semester-long project, 15 graduate students and 12 faculty (representing diverse fields in health, education and social services) entered into a distance relationship with Tomasi, Malia and their 3 children, communicating across the challenges of place and time, culture and language, and perceived imbalances in role and status. It is our hope that the story that follows will motivate others to build learning communities across distances

Family Focused Learning (FFL)

The UH Center on Disability Studies (CDS) through its MCH LEND program (Health Resources and Services Administration, Maternal and Child Health Bureau) sponsors interdisciplinary courses that use a mentorship model in which a learning community of students across disciplines (including public health, social work, physical therapy, speech pathology, nursing, special education, nutrition, medicine, political science and law) are mentored by their

respective faculty to study issues of culture and disability. The MCH LEND Program is a leadership development program designed to respond to national maternal and child health (MCH) and local initiatives to meet the essential intervention and health care services required for children with special health care needs and their families.

A core value of this MCH LEND learning community is to build partnerships between "helping professionals" and families of children with disabilities to promote problem-solving, creativity, and mutual respect. This has not been an easy challenge, as there is a long history of distance and imbalance between professionals and consumers, including the "expert" and "medical" models of service provision, in which professionals are expected to know the answers, and consumers are expected to listen and comply. It is our commitment to replace these worn-out paradigms with models of partnership, family-centered supports, and joint ownership of the problem-solving process (Rocco, Metzger, Zangerle, & Skouge, 2002).

Additionally, the MCH LEND model incorporates aspects of problem-based learning or case-based learning (Albanese & Mitchell, 1993; Barell, 1998; Bruner, 1987; Gardner, 1983; Ratliffe et al., 2000; Robinson, 1999). Both are approaches that have successful histories in medical schools, and in many other educational contexts including university-level special education courses. For example, problem-based learning in medical schools typically consists of a sequence of tutorials in which a vignette is presented to a group of students who "develop hypotheses, discuss underlying mechanisms, and prepare learning issues for clarification and discussion at the next session" (Katsikitis, Hay, Barrett, & Wade, 2002, p. 279). Case-based learning is similar, although a series of vignettes may be presented in a single session (Katsikitis et al., 2002). (For a comprehensive review of research of problem-based learning in medicine, see Albanese & Mitchell, 1993).

Realistic or authentic cases can provide veridical context-laden situations with all of the unique richness and complexities of individual lives, particularly when students and professionals engage with people in real settings, not just paper-based vignettes. A central tenet of Family Focused Learning (FFL) is the co-engagement of professionals and families learning together.

Furthermore, in learning about disability, students and professionals can no longer study without engaging real people within cultural contexts. These notions also have their roots in Vygotsky's sociocultural perspective (Vygotsky, 1978), in which learning and development can only be understood within the cultural settings in which they are situated.

In the Pacific region, disability studies are complicated by professionals from many different fields needing to learn about the cultural contexts and backgrounds of children, a task that is daunting, considering that the Pacific Ocean, perhaps the largest geographic feature on the planet, is covered by thousands of islands. These islands and island groups are peopled by many different and distinct cultural and linguistic groups. Encountering a child sent to Hawai‘i to be treated for a disability or a medical condition offers little or no understanding of cultural context.

Well-intentioned professionals from developed countries, comparatively wealthy in material resources, may fail to comprehend the implications of educational and socioeconomic differences in developing regions, and the socio-economic challenges that many island families face. Additionally, Western professionals may not be aware of the often unexpected strengths and positive aspects of extensive cultural resources that support children and families in their home island communities and villages. Unawareness of these challenges and opportunities may lead to frustration when medical or educational recommendations are not followed through.

In 1996, the University of Hawai‘i’s MCH LEND Project began exploring video technology to document “family voices” and family experiences, which in turn could be incorporated into an inquiry based training curriculum (Ratliffe et al., 2000; Skouge, 1997, 2004b). Faculty mentors and select students began meeting with families in their homes to map the key elements of the family’s experiences in raising a child with a disability (Falvey, Forest, Pearpoint, & Rosenberg, 1993; Vandercook, York, & Forest, 1989). These elements include (a) the beauty of their family, (b) daily routines, (c) hopes and dreams for their child with a disability, (d) fears and nightmares, (e) needs, concerns and barriers, (f) strategies to thrive and overcome, (g) positive and negative examples of professional services, and (h) how professionals can be helpful to families. We asked families to tell us stories, believing that story-telling is a natural and comfortable communication form for self determination and consumer empowerment (Dowrick & Skouge, 2001; Dowrick, Skouge, & Galbavy, 1999; Skouge, 2004a, 2004b; Skouge & Boisvert, 2004; J. Skouge, M. Kelly, & K. Thomas, 2003; J. R. Skouge, M. L. Kelly, & K. Thomas, 2003).

Usually, by the second or third home visit, a bond would be established between the university representatives and the family, the “map” was complete and the stories had been identified and rehearsed. At that point, a camera, tripod and microphone were brought into the living room and the stories were recorded in an easy interview style. Every effort was made to simulate a “home video,” with the now-trusted faculty handling the camera and guiding the discussion. In addition to videotaping the interviews, “roll over” footage was shot of daily routines (e.g., feeding and bathing) and community activities (e.g., swimming, taking the bus, bowling). The video was then edited at the university into a 30-45 minute “video letter,” containing thematic “chapters” of the family stories (Skouge, 1997, 2004a, 2004b; Skouge, et al., 2003; J. R. Skouge, et al., 2003). Over the course of some weeks, these family stories were shared with our students as the focus for in-class discussion, research, writing, and a culminating face-to-face dialogue with the family.

Tomasi and His Family: Adapting the FFL to Telecommunications

In the fall of 1998, the MCH-LEND faculty decided to extend the FFL model to include a Samoan family living in American Samoa. The plan was to follow the protocol described above, utilizing telecommunications as one vehicle for face-to-face dialogue. (For a description of technology issues in American Samoa, see Iding & Skouge, in press). Several of our faculty were making regular visits to Tutuila (American Samoa's main island) and Tomasi and his family were already known to us through prior consultation services. By that time our confidence in the FFL model was high (at least with families living in Hawai‘i), so it was not difficult to persuade our 12 graduate faculty to commit the time and energy to a distance learning experiment.

Tomasi Jr. was an intelligent and healthy 6-year old with severe cerebral palsy, unable to speak, walk or otherwise function independently. Tomasi Jr. was born in American Samoa, giving him the rights to access American social services. His parents, Tomasi Sr. and Malia, however, came from economically depressed circumstances in Western Samoa (now called simply Samoa). They had little formal education and were landless in American Samoa, living in a tiny wooden homestead, a mile or so from the paved road in “the bush.” Tomasi Sr. worked the night shift, 6 or 7 days a week at one of the tuna canneries. Malia stayed home to care for

Tomasi Jr., his younger brother, Junior, and his sister Rachel. The land and homestead were owned by a matai (chief). Malia spoke only limited English. Tomasi Jr. spoke none at all.

The story that follows represents the greatest cross-cultural, distance education challenge that we had yet faced. Here was an immigrant family, largely disenfranchised in its own homeland, inexperienced with Western ways of health and education, entering into an uncharted relationship with graduate faculty and students at the University of Hawai‘i:

> "This writer had a long-standing relationship with Special Education in American Samoa, spending as much as 3 months a year working on the main island. I first met Tomasi Jr. at the Special Education Center. He was loved by his teachers and widely acknowledged as a bright boy stuck in a terrible, disabling situation. Instead of a wheelchair, he sat in a folding stroller with a blue canvas sling seat that seemed to swallow-up his tiny body. We would typically see him slumped forward, staring at his lap, with the biggest smile, the greatest laugh and one hand that could ever so slowly reach and grasp. Often he'd be holding a tiny plastic car or animal that he could move across his line of vision. With his imagination going wild, he'd make sounds and hum tunes of joy. He was a smart kid, we all knew, but it seemed like he was going nowhere.
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> One day I asked the teacher, Taufou, if she would go with me to visit Tomasi's family, explaining to her that we hoped Tomasi and his family might agree to join us in teaching our graduate students about serving children with disabilities and their families, including producing a video and a teleconference. Taufou enthusiastically agreed and suggested that we follow his school bus home, as she did not know the way. A note was slipped into Tomasi's backpack informing his parents that we would like to make a home visit the following day. "Would that be all right?" we asked. The next morning, Tomasi the courier, returned with their following response: "Please come, you will be welcome."
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> We arrived at 2:00 p.m. on the following day. The road was rough. The foliage of the jungle was hanging listlessly in the afternoon heat. Not even the insects were buzzing. Malia was standing in the clearing, in front of a tiny wooden house, side-by-side with three others, each on stilts, with a much larger house built of block nearby. Children peered from the screen-less windows. Their eyes were open wide, and they were whispering and watching.
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> The van driver unbuckled Tomasi from the front passenger seat and lifted him into his mother's arms. Malia smiled and laughed and hugged him as she greeted us and led the way up the three steps into the tiny cottage. Taufou and I followed, removing our shoes at the door and carrying them inside, aware that the dogs in the yard were eyeing them with anticipation. The living room contained two rough hewn wooden chairs, woven mats on the floor, a tiny television set on a crate in the corner, and an alter with crucifix and framed picture of Jesus. Tomasi was laid on the mats and immediately greeted by his younger brother and sister. We too sat on the mats at Malia's invitation, and before many minutes, Tomasi Sr.(her husband), appeared through a back entrance with a tray of red juice and store bought cookies. Smiling shyly he set the tray on the mats before us, and then sat down himself beside Malia. They loved Tomasi Jr. very much, they explained, and would do anything to help him.

> I enlightened them the best I could about how I represented the Center on Disability Studies at the University of Hawai‘i, and that we were interested in forming a partnership with a family such as theirs, in order for our students to learn about Samoan families and what it is like to raise a child with a disability. I particularly wanted them to understand that we were not a service organization, nor were we in any position to promise supports and services; that, instead, we were professors and students trying to learn from families how it is to raise a child with a disability and what professionals should know in order to be culturally responsive. To this day I do not know if Malia and Tomasi understood the intent of my communication, but in good faith, they agreed to participate."

Producing a Video Letter and Video "Map"

Our first challenge was to produce a video letter to be taken back to Hawai‘i. One of our colleagues, Martha Guinan, flew to American Samoa to assist with the video production. Martha is the mother of a child with Down syndrome as well as an accomplished "family facilitator" and videographer. The video camera, rather than being intrusive, proved to be a tremendous facilitator of communication and "story telling." After reviewing with Malia and Tomasi Sr. the elements of "mapping," we started with asking Malia to tell the story of Tomasi Jr.'s life from the time of his birth to the present. Next, we filmed Tomasi Jr.'s daily routine, which also provided an easy framework for story telling: getting washed and dressed; eating breakfast; riding the bus; engaging in school routines (morning circle, story time, computer, lunch, art, music, and community recreation); coming home from school; life in the living room (games and books); playing in the yard; going to church; eating supper, and going to bed.

What we found as we produced the video was that both Tomasi Jr.'s family and his teachers became invested in its outcome. Tomasi shared his garden. Malia showed us how she prepared foods and fed Tomasi mashed bananas. Tomasi taught us his hand-signs for communication. His teachers showed us how books could be adapted so he could turn the pages, and how Tomasi could communicate with picture boards, work the computer, and even run an electric train using adapted switches. The process of making the video seemed to create awareness, in which everyone wanted Tomasi to shine. Everyone learned from one another. Expectations for Tomasi were heightened. It took nearly a week to get all the shots and interviews, but finally the "map" was complete – we had given voice to the family to express its hopes and dreams. Malia chose to be interviewed in English. Tomasi was interviewed in Samoan.

Employing the Video as "Inquiry Based Learning"

The video was edited back in Hawai‘i, and shown during a 3 hour Friday afternoon session in our graduate forum. The video was divided into four thematic chapters, which were viewed and critiqued by students and faculty organized into teams. Samoan informants from UH were invited to participate on each team to answer questions and explain cultural ambiguities. The mission of the teams was to critically reflect on each of the chapters in terms of: (a) What are we hearing from Tomasi and his family? (b) What other information do we want or need? and, (c) What might be a learning issue to research that would help this family?

By the end of that first Friday session, a tremendous outpouring of student dialogue and questioning had been generated: "How do Samoans perceive disabilities, in terms of causes and expectations?" "What kinds of adaptations could be built for their home so that Tomasi could be more active and independent?" "How do Samoans balance traditional medicine with the 'palagi' or 'western ways'?" "Are there assistive technologies that could help Tomasi to learn and communicate (augmentative communication and computer software)?" "What is the Samoan diet?" "Where does a Samoan child fit into the family and community?" "What services and supports are available in American Samoa for children with disabilities?"

Each team prioritized a research topic, interviewed informants, conducted literature reviews, and then wrote reports in "family friendly" language for Tomasi's parents – sharing the information they had learned, along with questions they would like to ask the family during the upcoming teleconference. The tone of the reports was not to be expert or academic. The reports were more like letters to the family, with open invitations for dialogue and values sharing – respecting Malia and Tomasi as cultural informants and teachers. Several weeks were allowed for the writing of the reports. In order to share the reports with the family, they were presented in class and videotaped, with each team member introducing themselves, and sharing something personal with Tomasi's family, in addition to the report.

The Teleconference

We then returned to American Samoa in preparation for the teleconference. Taking a VCR and television to Malia and Tomasi's home, the team presentations were viewed in the family living room, along with the written reports. Tomasi's teacher, Taufou (the same person who had assisted in the production of the video), accompanied us for the family meeting. Each team presentation was viewed and discussed in Samoan language. Tomasi and Malia rehearsed what they would like to say in response to each of the reports. A written outline was created, which included both things to say and things to show (including various foods, traditional medicines, and positioning devices for Tomasi, including a stroller and a corner chair). Malia chose to write a letter in English to each of the teams, thanking them for their research and answering select questions. These letters were subsequently read aloud during the teleconference.

The teleconference was scheduled for a 3 hour block on a Friday afternoon, utilizing the Peace Satellite link between the University of Hawai'i and the LBJ Hospital on Tutuila. We were scheduled to pick up the family at 11:00 a.m., in order to make it to the LBJ Hospital by noon. Malia, her mother, Tomasi Sr., Rachel, Junior, and Tomasi Jr. were waiting with great anticipation in the clearing when we arrived. They were all wearing new clothes, which Malia had sewn by hand. She looked at us with a half-hearted smile, whispering that they were all very nervous. It was perhaps then that we first realized the seriousness of this experiment. Here was a family, without economic means, struggling on the very margins of Samoan society, raising a child with severe cerebral palsy, engaged in a relationship with professors and their students from a world far, far away – connected by video from a humble shelter in American Samoa to an air conditioned classroom on O'ahu. They were probably thinking, "And now what? A teleconference?" It is doubtful that Tomasi Jr. and Malia could imagine what this event would be. It was an act of faith to climb into the truck and embark on the road to town.

We arrived at the hospital. The teleconference facility was ready. Tomasi's teachers and other special education invitees were waiting. Tomasi and his family were positioned in the

front of what was becoming a throng. A technician turned on a large television set. And there, flickering to life, came the faces of the 30 or so "friends" across the water – professors, graduate students and Samoan cultural brokers. There was Martha's face, familiar and comforting, greeting us from Hawai'i. Everyone took their turn to say, "Hello." The process was orchestrated with Martha facilitating one end, and Taufou and one author facilitating the other.

The papers were discussed one at a time, with care taken that Malia and Tomasi spoke first to each of the papers, with prompts and supports from the facilitators. Malia read her letters. Tomasi Jr. spoke in Samoan, with Taufou translating. Malia demonstrated Samoan massage. Students in Hawai'i showed pictures of an adapted swing that could hang from the tree in the clearing. The 3 hours flew by, amid tears and laughter. All too soon, it was 3:00 and time to say good-bye. The television was turned off and we bundled ourselves back into the truck.

We negotiated the traffic and returned to the clearing, carrying Tomasi into the tiny room that was the center of family life. We sat on the mats, as we had so many times before, to debrief and try to figure out what we had just experienced. Malia told us she could not express the gratitude she and her family felt for all that had happened. They did not feel invisible anymore. It was acceptable to have dreams for themselves and for their son. She had never felt shame for having a child with a disability, but she had never before been empowered to say it. She expressed these sentiments by saying, "And to be with people, educated and knowledgeable and powerful who could listen!"

In Hawai'i, too, the faculty and students expressed a need to debrief. Here was a family they had come to know so well, a discussion that had been so intimate and revealing, between people seemingly far away…but not.

In the months that followed Malia, Tomasi and their family moved to Hawai'i, in order for Tomasi to benefit from Western medical and educational supports. Their saga in Hawai'i has been filled with a mixture of joy and pain, but that is for another story at another time. For our purposes here, let us say that many of our MCH LEND students and faculty rallied in support of this beautiful family to assist them with finding housing, social welfare services, and special education. The bonds of friendship had been forged.

Conclusion

In this article, we illustrate Family Focused Learning by sharing the story of Tomasi, because we believe it to be one of the most effective ways to convey the process of learning about and with a child who has a disability and his family in his own unique cultural context.

Central to the effectiveness of this collaborative "learning community" model are the notions of respect and the willingness of a disparate group of people from different backgrounds to work together. A unique feature of this model involves the child with a disability and his family acting as teachers for an interdisciplinary group of faculty and students from diverse disciplines.

Central also is the use of video and telecommunications technology to create links between families, medical/educational professionals and students that would otherwise be separated by thousands of miles of ocean and vast cultural and socioeconomic divides. It is our hope that this can serve as a useful model for other cultural contexts, as professionals learn to work effectively and respectfully with children with disabilities and their families, and to learn from them as well.

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Martha M. Guinan is a Program Specialist for the Center on Disability Studies at the University of Hawai‘i providing family supports to persons with disabilities and their families. She has long held an interest in empowering technology, including giving voice through video. She is a candidate in the doctoral program in Special Education.

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